Quality of Life of Chinese Heart Failure Patients and Their Family Caregivers

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Abstract

Quality of life has become an important aspect in the assessment and treatment process of chronic disease. The aims of this study were to determine the factors affecting patients and their caregivers' QOL and compare the QOL of participants. The data were collected using Short Form 36 in Chinese version one. QOL of the Heart failure patients was less than their family caregivers and HF patients'. QOL was affected by gender, employment status and education level and it was not to be affected by marital status and New York heart association classification, Also this study was determined that heart failure family caregivers' QOL was affected by gender. HF seriously affects patients' and their family caregivers' QOL and caregivers have better QOL than patients.

Keywords: Heart failure patients - family caregivers - quality of life - nursing – SF-36

Introduction

Cardiovascular disease is associated with high mortality, morbidity and poor QOL, and poses a considerable economic burden; it is the third leading cause of death in the United States(Lloyd et al.,2009; Lopez, 1993)also it is the first leading cause of death in the P.R. China (China report 2010). HF maybe the final and most severe manifestation of nearly every form of cardiac disease and it is a complex disease with serious consequences for patients and their family caregiver. It is defined as the heart's inability to pump sufficient blood to maintain adequate tissue perfusion and compensatory neurohormonal mechanisms (American Heart Association, 2007). HF constitutes a major health problem worldwide; its prevalence is on the increase as people are living to advanced age as a result of improved medical therapies (American Heart Association, 2007). It is associated with high mortality rates, frequent hospitalizations, physical and cognitive impairment as well as reduced QOL (American Heart Association, 2007). Maintaining a good QOL is as important as survival for most patients living with a progressive or chronic disease (Lewis et al., 2001). QOL is a multidimensional construct that incorporates the physical, mental, psychological, social and spiritual functioning of the individual and it used to understand the effects of the disease on the patient (Guyatt et al., 1988) and their family caregiver.

It is increasingly incorporated as an outcome in treatment process of HF patient as it is important to understand how the patient reacts to the treatment process (Lloyd et al., 2009). HF patients have a significantly impaired QOL compared to those with other chronic illnesses as well as healthy population (Juenger et al., 2002; VanJaarsveld et al., 2001; Dixon et al., 2002). QOL, symptom burden and emotional well-being in HF patients is indeed as poor as in patients with malignant cancer (O'Leary et al., 2009). HF patients have impaired cognition and suffer from debilitating physical symptoms (dyspnea, edema, fatigue and pain), frequent hospitalizations, forced retirement, role changes, financial pressure and disruption of the usual sources of social support.

All of these characteristics and changes can lead to limited daily physical and social activities and result in depression and reduction in QOL in both patients (Jaarsma et al., 1999; Wilson et al., 1999; Rector et al., 2006), and family caregivers (Vaccarino et al., 2001), and poor QOL can lead to increase morbidity and mortality rate of HF patients (Vaccarino et al., 2001). HF patient relies on his family caregiver in medication administration, symptom monitoring and management, shopping, cleaning, cooking, bathing, dressing and transport. So, the family caregiver is faced with a huge responsibility which can have a negative impact on their life. Some studies indicate a decline in health, deteriorated life changes, lower ratings of life satisfaction (Luttik et al., 2005; Meagher-Stewart et al., 2002), and QOL compared to the general population (Kershaw et al., 2004; Markowitz et al., 2003 ; Weitzner et al., 1999). Nurses should assess HF patients and their family caregivers, and educate them about the disease process, life style changes, activity, care needs, diet and fluid restrictions, nutrition, medications, smoking cessation, alcoholic intake limitations, and signs and symptoms of worsening HF (Anna et al., 2009). So HF patients and their family caregivers are often required to follow complex schedule of therapeutic regimens and undergo multiple life style changes in order to optimize their QOL. Therefore, the purposes of this study were to determine the factors affecting patients and their caregivers' QOL and to compare the QOL of HF patients and their caregivers.

Methodology

The study was approved by the ethics committees of the nursing collage and permission was granted to conduct this study. Written consents were also obtained from the Manager of the Department of the Nursing, and Head of Nurse of each Cardiovascular Department in Union Hospital. It is a comparative descriptive study of quality of life in HF patients and their family care givers. The study was conducted in a general teaching hospital in Wuhan city of P.R. China. A total 200 participants (200 HF patients and 200 family caregivers) participated in the study and the data were collected during one complete calendar year (September 2010-september 2011) After approval to conduct the study was obtained from the hospital administrators, physicians and head nurses, the procedures for data collection was the following: The privacy was maintained during the interview by talking to participants in their individual treatment room in hospital; The investigator introduced himself to patient and their caregiver by face to face interview; Participants were informed about the aims of the study by a brief explanation and a detailed letter explaining the study and that their participation is voluntary. If the participants met the selection criteria and express interest to participate in the current study verbal informed consent is obtained from both of them .participants that were eligible were asked to complete the questionnaires independently. Participants completed the questionnaire with the investigator in attendance and available to answer and explain any questions.

Participants had to be at least 20 years old or over, not suffer from any mental health problem, visual or auditory impairment, able to speak, understand, read and write Chinese language and also the Caregiver must be a non-paid family member or significant other of the HF patient, should identified by the patient as a person who provide the mental and physical support. When both patient and family caregiver met the selection criteria and express interest to participate in the current study verbal informed consent is obtained from both of them .participants who were eligible were asked to complete the questionnaires independently. Participants completed the questionnaire with the investigator in attendance and available to answer and explain any questions. The instruments for data collection were composed of two parts: the demographic data questionnaires and Short Form Health Survey SF-36 (Chinese version1) questionnaires for HF patient and their family caregiver. Demographic data form which was developed by the researcher and it was used to collect some basic characteristic information which consist of patients and family caregivers age, gender, education level, marital status, employment status and NYHA. Short Form Health statues SF-36(Chinese version one): The SF-36 questionnaire was developed by Ware (Ware, 1994; Ware, 2000). In fact the sf-36 is the most widely used (Hubanks ; Brazier et al., 1992), and it's a validated, reliable and multidimensional generic of quality of life (Ware et al., 1992; McHorney et al., 1993).

It was designed to provide self–evaluation of quality of life which summarized that essence of conception of the health. It has been translated for use in many countries like China, Brazil, Armenia, Israel, South Africa and United Kingdom. Short form-36 health status questionnaire consists of 36 questions, one transition question that asks the patient to measure the amount of change in general health that he/she experienced during the past year and the other 35 questions remaining that rate the quality of life a long eight dimensions, the dimensions fall into two consecutive group: physical component score (PCS) that consist of the Physical Function (PF);

Role Physical (RP); which refers to role limitation due to physical difficulty; Bodily Pain(BP); General Health (GH) and mental component score (MCS) that consist of the Vitality (VT); Social Function (SF); Mental Health (MH); Role Emotion (RE)which refers to role limitations due to emotional difficulties and mental health. The reliability of SF-36(Chinese version one) in this study is 0.888. All statistical analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 14.0 .For the quantitative research, the demographic information of HF patients and family caregivers were analyzed using descriptive statistics, including Means(M), standard deviations (SD), ranges, frequencies and percentages were used to describe demographic information's of participants. Analysis was carried by using independent t-test or variance (ANOVA) to examine whether if there is a statistically significant difference could be demonstrated between the mean subscale scores and total scores for participants. And also Pearson correlation coefficient is used to study the correlations of quality of life between scores on the patient's scale and score on the caregiver's scale. A value of $P< 0.05$ was considered statistically significant for the purposes of the study.

Results

206 eligible participants were obtained from cardiology unit of Union hospital, composed of the sample. 6 patients and their family caregivers did not complete the questionnaire accurately or one of the participants declined to participate. Total 200 eligible couple completed questionnaire. Socio demographics characteristics of the patients and their family caregivers are shown in the table 1.The average age of patients was 60.969(14.847)years and the average age of their family members was 44.48 (13.99) years, 86 (43%) of the heart failure patients were male and 114 (57%) were female, 102(51.78) of the family caregivers were female and 95(48.22) were male.(8.94) of the patients were married and 173 (86.93%) of the patients family caregivers were married. 44 (25.14) of the heart failure patients had completed their junior middle school and family caregivers 62 (31.3) had completed their senior middle school. At the time of data collection, most patients were Unemployed 133 (68.91%) and 56(28.57%) of their caregivers were workers and 48 (24.49%) were business man. 165(82.5%) of the subjects had no religion, 58 (29.9%) of the subjects had a monthly income of 4000 to 6000 Yuan. 3.55 (3.7%) was the patients number of hospitalization, 1.26 (0.53%) caregivers had health problem and 59(30.1%) patients had other diseases. 51.37(16.9%) of the patients had a left ventricular ejection fraction (LVEF), 70 (37.04%) of the patients where in Class II and 65 (34.39%) were in Class III. 92(46%) caregivers were patients' Son/daughter and most family caregivers didn't share caregiving with anyone. The mean duration of caregiving was 372.85 days (SD =1280.7days). Almost 116 (58.88%) of the Caregiver know and feel giving care is very important and they do it from the heart and love. 120 (60%) of the participants were living together.

The SF-36 consists of eight domains and it was used to compare the participants' QOL. Table 2 shown that HF patients and their family caregiver's total QOL had statistically significant difference .The patients QOL scores were lowest on the physical function (t= -18.05, p=0.000),role physical (t=-7.09, p=0.000), body pain (t=-12.56, p=0.000), general health (t= -8.71, p=0.000), energy vitality (t= -15.77, p=0.000),but patients social function dimension (t=-0.13 , p=0.89), emotional role (t=-0.15, p=0.88) and mental health dimension (t=-0.39 , p=0.069), of QOL scores were not significantly different than their family caregivers' social function, emotional role and mental health dimensions of QOL scores.

Table 3 and 4 shown if the socio-demographic factors of the participants were associated with the QOL, the Independent T-test was used to compare the total QOL scores for patient and their family caregiver in relation to gender, marital status and employment status and also we used ANOVA test to compare the total QOL scores for patient and their family caregiver in relation to educational level and NYHA. Table 3 shown that the marital status (t= 0.49, p = 0.6257), NYHA (F= 0.19, P=0.92) did not affect the patient's total QOL (Table 3).but the gender (t= -2.51, p = 0.0128), education level (F= 3.05, p= 0.0116), employment status (t = 3.73, p = 0.0003), affected the patients' QOL. When the mean total QOL scores were examined according to the gender, male patients reported that had statistically significant higher mean QOL scores than female patients; patients who employed reported that had statistically significant higher mean QOL scores than caregivers who did not employ and also patients who had high educational level reported that had statistically significant higher mean QOL scores than patients who illiterate or had low educational level.

In the table 4, there was no statistically significant difference between caregiver's total QOL scores and their education level (F=0.93, p= 0.4624), marital status (t=0.84, p= 0.3995), employment status (F=0.17, p=0.8640), NYHA (F=1.09, p=0.3530).

But, the gender affected the caregivers' QOL. When the mean total QOL scores were examined according to the gender, male caregivers reported that had statistically significant higher mean QOL scores than female caregivers. (t =-6.18, p= 0.0001)

Pearson correlation tests were carried out to check the relation between QOL of patient in relation to their family caregiver. The result showed that there was no significant correlation between patients' and their family caregivers' QOL Patient's physical function, role physical, general health bodily pain (PCS) Mental Health, Social Function, Vitality, Role Emotion (MCS) and total QOL scores were not significantly correlated with total scores or any subscale of caregiver's QOL at the 0.05 significance level in a two tailed test of significance.

Discussion

The purpose of this study was to determine the factors affecting HF patients' and their family caregivers' QOL. In this study, it was determined that HF patients' QOL was affected by gender, employment status and education level and it was not to be affected by marital status and NYHA. Also this study was determined that HF family caregivers' QOL was affected by gender and it was not to be affected by employment status, education level, marital status and NYHAC. The Gender have been reported to affect the HF patient QOL, female HF patient are more impaired in mental health and physical health than the male HF patient (Friedman, 2003; Leegte et al., 2006).

Reidinger et al. (2001) indicated that female patient had significantly worse in the physical function domain than male patient. The QOL of HF patients was affected by gender; however the findings of this study revealed that the QOL was negatively affected in female patient with HF, maybe because the Chinese female patient more weak and sensitive naturally so she don't have the endurance and ability to adapt with her pain, fatigue, stress, guilt and anxiety like male patient .Individuals who are divorced or never married are more likely to die from heart disease than married patients ((Lynch, 1990). The previous research shown that having support of the caregiver is essential for outcomes in HF patients (Marie et al., 2005). The HF patient who is socially isolated was significantly related to an increase in the rate of the hospitalizations (Struthers et al., 2000). In other study also indicated that patients who did not have an informal career had a worse QOL than those who could identify a career. It has been shown previously that QOL in HF patients having a marital relationship is better than the congestive HF patients living alone (Luttik et al., 2006). Single HF patient has been independently associated with frequent hospitalization and increase the death rate (Chin et al., 1997). but married patient is associated with higher levels of perceived social support (Lofvenmark et al., 2009).

Marital status greatly affected the QOL of HF patients. In contrast to many studies, in this study 177 patients were married so we can't determine if the QOL of heart failure patients was affected or not by the marital status because a big portion of this sample were married. The QOL of employing patient with hemodialysis has better than who not employing and the physical components summary of employing patient is better than not employing or retired patient (Emad et al., 2012). (Filazoğlu (2008) stated that female who employed reported higher levels of QOL than who not employed. In our study patient employment status was affected their QOL and HF patient who employed had better QOL than patient who unemployed, One possible reason could be that employment patient have daily activity and work capacity that decrease the pressure, stress and anxiety also improve the patient physically, socially and financially and reduce the economic burden. Also, they could communicate with more people and decrease the emotional burden.

Patient with higher education level have better assimilation for the disease and treatment process and easier access to good QOL (Giorgio, 2011) previous studies have shown that HF patient with lower education level suffering from poor QOL (Giorgio, 2011) such as lower levels of physical functioning, higher anxiety and poorer general health (Riedinger et al.,2000). In another study was shown that low-educated patients with HF were less likely to extradite care from a cardiologist (Auerbach et al., 2000), and reported more than a 50% increasing the risk of hospitalization compared with the patients with high educated level (Sui X et al.,2008). In another study Patients with low educational levels reported the worst physical and functional so these sorts of patients need different levels of intervention to improve their physical and functional circumstances but high-educated patients have progress and development more than the other patients and have better QOL (Doris et al.,2004). However in contrast to the other studies, in this study HF patients' educational status was affected their QOL and it was closely associated with the QOL in these patients.

The patients graduated from diploma had higher level of QOL than Illiterate and those graduated from primary and/or secondary schools, maybe because the high educated patient have good ability to adapt and coping with his disease also extradite care from a cardiologist and nurse .

Clinical factors that lead to poorer QOL are progressing disease severity and an increasing burden of co-morbidity (Friedman, 2003; Pressler et al., 2010). High NYHA class was lead to low physical health (Emma et al., 2005), and poor QOL in the HF patients (JavaidIqba et al., 2010). In this study the majority of the HF patient was in NYHA class II and patient NYHA classification was not affected their QOL. Female caregivers have been associated with more distressed than male caregiver (Lutzky, 1994; Yee et al., 2000) and Female partners had lower levels of emotional well‐being (Evangelista et al., 2002; Walden et al., 2001) In another study have shown that female caregiver report a higher need for support than male caregiver Cowie et al., 2002; Bookwala et al.,1998). In contrast to many studies this study also found the QOL was negatively affected by gender; however the findings of this study revealed that the QOL was negatively affected in female caregiver of HF patient more than male caregiver, maybe because female caregivers reported more suffering and difficulty in the operation of helping behaviors to the patient with HF (Karmilovich ,1994), and also the female more anxiety and she have strong obligation to patients. The family caregiver of HF face many difficulty issue (Martensson et al., 2003) that can affected his QOL and it seems that have a close relationship to the care recipient and being young are both associated with poorer mental health outcomes for caregivers (Cantor, 1983).

In Adawalla et al (2007) study shown that caregivers who married had higher QOL, however this study findings showed that caregiver marital status was not affected their QOL. female caregiver who continued his work, activities and who had satisfying marriages were less distressed one year after their patient became sick ,employed caregivers who giving care for stroke patients where at higher risk of depression than the unemployed caregiver (Rohrbaugh et al., 2002). Adawalla et al (2007) found the QOL of cancer patients were negatively affected in caregivers who not maintain employment status. Employed caregivers accepted higher well‐being, suggesting the benefits of work to caregiving than unemployed caregivers of older HF patients(Saunders 2010) In this study 181 caregivers were employed so we can’t determine if the QOL of the family caregivers of HF patients was affected or not by the employment status because a big portion of this sample were employed. Caregiver of stroke patient with low education level had lower level of general health (Grant et al., 2001) Adawalla et al (2007) reported that the education of cancer patient was associated with higher caregiver QOL. However In this study the caregiver who graduated from diploma had higher level of QOL than Illiterate and those graduated from primary and/or secondary schools but the educational status was not significant factors in a family caregiver QOL. Disease severity (higher patient NYHA class) (Barnes et al., 2006), lower caregiver economic status (Hooley, 2005) were associated with a more unfavorable impact on the heart failure caregiver. Rohrbaugh at al (2002) found that NYHA class was not related to family caregiver emotional distress, while Martensson et al., (2003) found that, perhaps higher NYHA class was related to poorer mental health of the family caregiver. In contrast to many studies our study found NYHA was not significant factors in a family caregiver QOL.

The second purpose of this study was to compare the QOL of heart failure patients and their family caregivers and determine whether the QOL of HF patient is associated with the QOL of their family caregiver.

HF patients suffer from common complications such as: breathlessness, persistent cough, sleep disturbance, fatigue, and limitation in physical activity, anxiety, emotional distress, depression, nausea and constipation (Metra et al., 2007; Blinderman et al., 2008; Janssen et al., 2008). These complications impose additional pressure on patients and their family caregivers which further impinge on their QOL. HF is a progressive chronic disease with debilitating effects on patients’ lives. As a result, the QOL of HF patients is of inferior quality to that of the general population (vanJaarsveld et al., 2006) and more incapacitating compared to healthy elderly population (Lesman et al., 2009). Furthermore, the QOL of patients with HF was described as of poorer quality when compared to that of patients with other chronic disease such as diabetes mellitus and chronic lung disease, and remains at least as bad as that of patients with malignant cancer in both male and female (Stewart et al., 2001). Previous studies indicate that HF family caregivers have an inferior QOL to that the HF patients themselves; however, these findings are still inconclusive (Luttik et al., 2005; Martensson et al., 2003).

Martensson et al., (2003) found a worse or equal QOL in the HF patients compared with their family caregivers. Luttik et al., (2005) found preference for the heart failure family caregiver's QOL to be lower than the QOL of patient themselves. In this study overall QOL domains of the HF patients sample were lower than their family caregivers. HF Patients' and their family caregiver QOL consists of PCS and MCS and for the patients PCS and MCS almost similar, but for their family caregivers' mental component score was worse than the physical, maybe because the culture in china supports sick patients, family members, and friends. When a person gets sick, both society and traditional values expect the family members to take care for that person's and support him financially. Moreover, religiosity increases life satisfaction, reduce anxiety and depression McMillan (1994) also encourage the good habits but high percent of Chinese peoples were no religion.

Martensson et al., (2003) shown that patients were worse physical QOL than the family caregivers But the Mental QOL did not differ between patients and their caregiver. Rohrbaugh at al (2002) also found high levels of psychological distress in HF patients as well as in their family caregiver. Other researchers who have compared QOL of family caregiver and patients with other chronic illnesses found that patients with visual acuities had lower QOL in all dimensions compared to their family caregiver (Carpenter et al., 2009). Jönsson et al., (2005) also find stroke patients had lower QOL in all the domains except the mental emotional compared to their caregiver. In this study patient with HF had worse QOL compared to their family caregivers, and this study also found HF patients' mental health, emotional role and social function dimension of QOL scores were not significantly different than caregivers' mental health, emotional role and social function dimension of QOL scores. Mcmillan et al (1994) was found that no significant correlation was found with the social domain. Other researchers who have compared mental and physical components of the patients and their family caregiver with Hemodialysis found that patients' mental and physical components did not correlate with caregivers' mental and physical components (Emad et al., 2012). In this study, the patients' all dimensions of QOL did not correlate with caregivers' total and sub-dimensions of QOL, it was thought that this lack of correlation may be due to the Chinese patients tendency to not to clearly report their feelings even when they are severely pain and distressed. So, family caregivers may not perceive patients' status.

Conclusion

The finding of this study is clearly showed that HF seriously affects patients' and their family caregivers' QOL and caregivers have better QOL than patients. And also Patients mental health, emotional role and social function were not significantly different than caregivers' mental health, emotional role and social dimension of QOL scores.

Patients previous researches have demonstrated that disease severity and the several socio-demographic factors were affected both patients and caregivers' QOL. However the findings showed that gender, marital status, education level and employment status did not affect factors the QOL in 200 patients with HF.

In this study also revealed that caregivers' QOL was not affected by gender, education level and marital status. Only, in this study, maintaining employment status was affecting the QOL of caregivers.

In order to improve the QOL of both patients on heart failure and their family caregivers the government and Non-Governmental Organizations need to support these groups of people and work on improving the caregiver's QOL in order to improve the heart failure patient's QOL. cardiology nurses should assess affecting factors of patient's and caregiver's QOL and inform their knowledge, experiences, communication skills, financial planning, distress management skills, improve treatment compliance, share ways to handle crisis and spirituality topics would affect patients and caregivers burden and QOL.

Limitations

Several limitations of this study need to be acknowledged. First, a cross –sectional design was used, the finding of this study could be more strengthen and provide a more accurate picture by use of a longitudinal design. Second, the research was conducted in one province in the central of china (Hubei province) and only one hospital of the results is limited either to the whole population of Hubei province or the whole population of china.

References

American Heart Association (2007). Heart Disease and Stroke Statistics – 2007 Update.Last accessed on August 4, 2007 from http://circ.ahajournals.org/cgi/content/full/CIRCULATIONAHA.106.179918

Anna Marie Knopp. NURSES' KNOWLEDGE OF HEART FAILURE GUIDELINES IN A WESTERN MONTANA HOSPITAL. April 2009 from http://etd.lib.montana.edu/etd/2009/knopp/KnoppA0509.pdf

Abdel-Khalek, A. (2010). Quality of Life, Subjective well-being, and religiosity in Muslim college students. *Qual. Life Res., 19*, 1133-1143

Auerbach AD, Hamel MB, Califf RM, Davis RB, Wenger NS, Desbiens N, et al. Patient characteristics associated with care by a cardiologist among adults hospitalized with severe congestive heart failure. J AmerCollCardiol 2000;36:2119e25

Awadalla AW, Ohaeri JU, Gholoum A, et al (2007). Factors associated with quality of life of outpatients with breast cancer and gynecologic cancers and their family caregivers: a controlled study. *BMC Cancer*, 19, 102.

Barnes S, Gott M, Payne S, et al. Characteristics and views of family carers of older people with heart failure. *Int J PalliatNurs*. 2006;12(8):380-389.

Brazier J, Harper R, Jones N, O'Cathain A, Thomas K, Usherwood T, et al. Validating the SF-36 health survey questionnaire: new outcome measures for primary care. BMJ 1992;305:160– 4.

Bookwala J, Schulz R. The role of neuroticism and mastery in spouse caregivers' assessment of and response to a contextual stressor. J Geront, Ser B PsycholSciSocSci 1998;53:P155–64.

Blinderman CD, Homel P, Billings JA, et al. Symptom distress and quality of life in patients with advanced congestive heart failure. J Pain Symptom Manage 2008; 35:594–603.

Carpenter DM, Thorpe CT, Lewis M, Devellis RF, Hogan SL.(2009) Health-related quality of life for patients with vasculitis and their spouses. Arthritis and Rheumatism. 61,259-265.

Chin, M. H., & Goldman, L. (1997). Correlates of early hospital readmission or death in patients with congestive heart failure. *The American Journal of Cardiology*, *79*, 1640-1644.

Cowie MR, Fox KF, Wood DA, Metcalfe C, Thompson SG, Coats AJS, et al. Hospitalization of patients with heart failure—a populationbased study. Eur Heart J 2002;23:877–85.

Cantor MH. (1983) Strain among caregivers: a study of experience in the United States. *Gerontologist.* 23, 597–604.

Doris S.F. Yu, Diana T.F. Lee& Jean Woo. Health-Related Quality of Life in Elderly Chinese Patients with Heart Failure. Research in Nursing & Health, 2004, 27, 332–344.

Dixon T, Lim LL, Oldridge NB. The MacNew heart disease health-related quality of life instrument: Reference data for users. Qual Life Res Mar;2002 11(2):173–183. PubMed: 12018740.

Emad A. Shdaifat, Mohd R. Abdul Manaf (2112). Quality of Life of Caregivers and Patients Undergoing Haemodialysis at Ministry of Health, Jordan. *International Journal of Applied Science and Technology Vol. 2 No. 3; March 2012*.

Evangelista L, Dracup K, Doering L, Westlake C, Hamilton MA, Fonarow G. (2002) Emotional well-being of heart failure patients and their caregivers. Journal of Cardiac Failure. 8, 300-3-5.

Emma Pihl, Anna Jacobsson, BengtFridlund, Anna Strfmberg, Jan Martensson. Depression and health-related quality of life in elderly patients suffering from heart failure and their spouses. The European Journal of Heart Failure 7 (2005) 583– 589.

Filazoğlu G, Griva K (2008). Coping and social support and health related quality of life in women with breast cancer in Turkey. *Psychol Health Med*, 13, 559-73.

Friedman M. Gender differences in the health related quality of life of older adults with heart failure. Heart Lung 2003; 32:320–327.

GIORGIO BARBARESCHI, PhD,ROBBERT SANDERMAN, IVONNE LESMAN LEEGTE, RN, DIRK J. VAN VELDHUISEN. Educational Level and the Quality of Life of Heart Failure Patients. Journal of Cardiac Failure Vol. 17 No. 1 2011.

Grant, J.S., Elliott, T.R., Giger, J.N., &Bartolucci, A.A. (2001). Social problem-solving abilities, social support, and adjustment among family caregivers of individuals with a stroke. *Rehabilitation Psychology, 46*(1), 44-57.

Guyatt, G.H., Sullivan, M.J., Fallen, E.L., Tihal, H., Rideout, E., Halcrow, S., et al. (1988). A controlled trial of digoxin in congestive heart failure. American Journal of Cardiology, 61, 371–375.

Hooley PJ, Butler G, Howlett JG. The relationship of quality of life, depression, and caregiver burden in outpatients with congestive heart failure. *Congest Heart Fail.* 2005;11(6): 303-310.

Hubanks L, Kuyken W. Quality of life assessment: an annotated bibliography. Geneva: World Health Organization, Division of Mental Health.

Juenger J, Schellberg D, Kraemer S, Haunstetter A, Zugck C, Herzog W, Haass M. Health related quality of life in patients with congestive heart failure: Comparison with other chronic diseases and relation to functional variables. Heart Mar;2002 87(3):235–241. PubMed: 11847161.

Jaarsma T, Halfens R, Huijer Abu-Saad H, Dracup K, Stappers J, Van Ree J. Quality of life in older patients with systolic and diastolic heart failure. Eur Heart J 1999;1:155 –60.

Jonsson AC, Lindgren I, Hallström B, Norrving B, Lindgren A. (2005) Determinants of quality of life in stroke survivors and their informal caregivers. Stroke. 36, 803-808.

Janssen D, SpruitM, Wouters E, Schols J. Daily symptom burden in end-stage chronic organ failure: a systematic review. Palliat Med 2008; 22:1–11.

JavaidIqbal, Loraine Francis, Janet Reid , Scott Murray, and Martin Denvir. Quality of life in patients with chronic heartfailure and their carers: a 3-year follow-up study assessing hospitalization and mortality. European Journal of Heart Failure (2010) 12, 1002–1008, doi:10.1093/eurjhf/hfq114

Karmilovich SE. Burden and stress associated with spousal caregiving for individuals with heart failure. ProgCardiovascNurs 1994;9:33– 8.

Kershaw, T., Northouse, L., Kritpracha, C., Schafenacker, A., & Mood, D. (2004). Coping strategies and quality of life in women with advanced breast cancer and their family caregivers. *Psychology and Health, 19*(2), 139-155.

Lloyd –Jones,D.,Adam,R.,Carnethon,M.,et al.(2009)heart disease and stroke statistics -2009 update :a report from the American Heart Association statistics committee and stroke statistics subcommittee. Circulation ,119,e21-e181

Lopez AD. Assessing the burden of mortaIity from cardiovascuIardiseases[J]. WorId Health Star Q, 1993, 46(2):91-96.

Lewis EF, Johnson PA, Johnson W, Collins C, Griffin L, Stevenson LW. Preferences for quality of life or survival expressed by patients with heart failure. J Heart Lung Transplant Sep;2001 20(9):1016–1024. PubMed: 11557198.

Luttik, M.L., Jaarsma, T., Veeger, N.J.G.M., & van Veldhuisen, D.J. (2005). For better and for worse: Quality of life impaired in HF patients as well as in their partners.*European Journal of Cardiovascular Nursing, 4*(1), 11-14.

Luttik ML, Jaarsma T, Veeger N, van Veldhuisen DJ. Marital status, quality of life, and clinical outcome in patients with heart failure. Heart Lung 2006;35:3–8.

Leegte I, Jaarsma T, Sanderman R, et al. Depressive symptoms are prominent among elderly hospitalized heart failure patients. Eur J Heart Fail 2006; 8:634–640.

Lynch, J. J. (1990). The broken heart: The psychobiology of human contact. In R.Ornstein& C. Swencionis (Eds.). *The healing brain: A scientific reader*. New York: Guilford.

Lofvenmark, C., Mattiasson, A., Billings, E., &Edner, M. (2009). Perceived loneliness and social support in patients with chronic heart failure. *European Journal of Cardiovascular Nursing*, 8(4), 251-258.

Lutzky SM. & Knight BG. (1994) Explaining gender differences in caregiver distress—the roles of emotional attentiveness and coping styles. *Psychology and Aging.* 9, 513–519.

Lesman-Leegte I, Jaarsma T, Coyne JC, et al. Quality of life and depressive symptoms in the elderly: a comparison between patients with heart failure and age and gender matched community controls. J Cardiac Fail 2009; 15:17–23

McMillan SC, Mahon M (1994). The impact of hospice services on the quality of life of primary caregivers. *Oncol Nurs Forum,* 21, 1189-95.

Meagher-Stewart, D., & Hart, G. (2002). Social support and the quality of life of individuals with heart failure and stroke and their caregivers. *Canadian Journal of Cardiovascular Nursing, 12*(1), 17-30.

Markowitz J.S., Gutterman E.M., Sadik K., & Papadopoulos, G. (2003). Health-related quality of life for caregivers of patients with Alzheimer disease. *Alzheimer Disease and Associated Disorders, 17*(4), 209-214

McHorney CA, Ware J, Raczek AE. The MOS 36-item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care 1993;31:247–63

Martensson J, Dracup K, Canary C, Fridlund B. Living with heart failure: depression and quality of life in patients and spouses. J Heart Lung Transplant 2003;22(4):460– 7.

Metra M, Ponikowski P, Dickstein K, et al. Advanced chronic heart failure: a position statement from the Study Group on Advanced Heart Failure of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail 2007; 9:684–694.

Marie Louise Luttik, Tiny Jaarsma, Nic J.G.M. Veeger, Dirk J. van Veldhuisen. For Better and for Worse:*quality of life impaired in HF patients as well as in their partner. European Journal of Cardiovascular Nursing 2005; 4:11-14.*

O'Leary N, Murphy NF, O'Loughlin C, Tiernan E, McDonald K. A comparative study of the palliative care needs of heart failure and cancer patients. Eur J Heart Fail 2009;11:406–412.

Pressler SJ, Subramanian U, Kareken D, et al. Cognitive deficits and healthrelatedquality of life in chronic heart failure. J CardiovascNurs 2010;25:189–198

Rohrbaugh MJ, Shoham V, Cranford JA, Nicklas JM, Sonnega JS, Coyne JC. Couples coping with congestive heart failure: role and gender differences in psychological distress. J FamPsychol 2002;16(1):3– 13.

Riedinger MS, Dracup KA, Brecht ML. Quality of life in women with heart failure, normative groups, and patients with other chronic conditions. Am J Crit Care May;2002 11(3):211–219. PubMed:12022484.

Riedinger MS, Dracup KA, Brecht ML. Predictors of quality of life in women with heart failure. J Heart Lung Transpl 2000;19:598e608.

Riedinger, M. S., Dracup, K. A., Brecht, M. L., Padilla, G., Sarna, L., &Ganz, P.A. (2001). Quality of life in patients with heart failure: do gender differences exist? *Heart Lung, 30,* 105-16.

Rector TS, AnandIS, Cohn JN. Relationships between clinical assessments and patients' perceptions of the effects of heart failure on their quality of life. J Card Fail Mar;2006 12(2):87–92. [PubMed: 16520254].

Stewart S, MacIntyre K, Hole DJ, Capewell S, McMurray JJ. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *Eur J Heart Fail* 2001; 3:315-22.

Saunders MM. (2010) Working and caregiving: a comparison of employed and unemployed caregivers of older heart failure patients. Holistic Nursing Practicle. 24, 16-22.

Struthers, A. D., Anderson, G., Donnan, P. T., & MacDonald, T. (2000). Social deprivation increases cardiac hospitalizations in chronic heart failure independentof disease severity and diuretic non-adherence. *Heart, 83(1),* 12-16

.Sui X, Gheorghiade M, Zannad F, Young JB, Ahmed A. A propensity matched study of the association of education and outcomes in chronic heart failure. Int J Cardiol 2008;129:93e9.

vanJaarsveld CH, Ranchor AV, Kempen GIJM, et al. Gender-specific risk factors for mortality associated with incident coronary heart disease: a prospective community-based study. Prev Med 2006; 43:361–367.

VanJaarsveld CH, Sanderman R, Miedema I, Ranchor AV, Kempen GI. Changes in health-related quality of life in older patients with acute myocardial infarction or congestive heart failure: A prospective study. J Am GeriatrSoc Aug;2001 49(8):1052–1058. PubMed: 11555066.

Vaccarino V, Kasl SV, Abramson J, Krumholz HM. Depressive symptoms and risk of functional decline and death in patients with heart failure. J Am CollCardiol Jul;2001 38(1):199–205. PubMed: 11451275.

Ware JE, Kosinski MA, Keller SD. *SF-36 Physical and Mental Health Summary Scales: A User's Manual.* Boston, Mass: The Health Institute, New England Medical Center; 1994.

Ware JE. SF-36 Health Survey update. *Spine.* 2000;25:3130-3139. Also available at: http://www.sf-36.com.

Ware J, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care 1992;30:473–83.

Walden JA, Dracup K, Westlake C, Erickson V, Hamilton MA, Fonarow GC. (2001) Educational needs of patients with advanced heart failure and their caregivers. *Journal of the Heart and Lung Transplantation.* 20, 766–769.

Wilson JR, Hanamanthu S, Chomsky DB, Davis SF. Relationship between exertional symptoms and functional capacity in patients with heart failure. J Am CollCardiol Jun;1999 33(7):1943–1947. PubMed: 10362197.

Williams RB, Barefoot JC, Califf RM, Haney TL, Saunders WB, Pryor DB, Hlatky MA, Siegler IC, Mark DB. Prognostic importance of social and economic resources among medically treated patients with angiographically documented coronary artery disease. *JAMA* 1992; 267:520-24

Weitzner, M.A., Jacobsen, P.B., Wagner, H., Friedland, J., & Cox, C. (1999). The Caregiver Quality of Life Index- Cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research, 8*(1-2), 55-63

Yee JL & Schulz R. (2000) Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist.* 40, 147–164.

中国心血管病报告 2010》概要[J]，护理管理杂志，2012 年 01 期 http://www.cnki.com.cn/Article/CJFDTotal-HLGL201201005.htm

Table 1 Socio-demographic characteristics of the patients and their family caregivers:

Patients and their family caregiver Characteristics	**Patients (mean± S.D.) Number (%) (n=200)**	**Family caregiver (mean± S.D.) Number (%) (n=200)**
Age	60.97(14.847)	44.48 (13.99)
Gender		
• Female	114 (57)	95(48.22)
• Male	86 (43)	102(51.78)
Marital status		173 (86.93)
• Married	177 (88.94)	5 (2.51)
• Divorced	0 (0)	19 (9.55)
• Single	4(2.01)	2 (1.01)
• Widow/widower	18(9.05)	
educational level		
• Illiterate	18 (10.29)	2(1.01)
• Primary school	34 (19.43)	8 (4.04)
• Junior middle school	44 (25.14)	59 (29.8)
• Senior middle school	40(22.86)	62 (31.3)
• Diploma	33 (18.86)	42 (21.2)
• High education	6 (3.43)	24 (12.12)
Occupational background		
• Farmer	13 (6.74)	28(14.29)
• Worker	19 (9.84)	56(28.57)

• Teacher	4 (2.07)	14 (7.14)
• Business man	6 (3.11)	48 (24.49)
• Leader	14 (7.25)	29 (14.8)
• Else	4 (2.07)	3 (1.53)
• Unemployed	133 (68.91)	18(9.18)
Religion		
• Muslim	165(82.5	165(82.5
• No religion	113 (6.5)	113 (6.5)
• Buddha	9(4.5)	9(4.5)
• Christen	1 (0.5)	1 (0.5)
• Taoism	3 (1.5)	3 (1.5)
• else	9 (4.5)	9 (4.5)
Annual household income(Yuan)		
• ＜2000	43 (22.1)	
• 2000～	55 (28.35)	
• 4000～	58 (29.9)	
• 6000～	21(10.82)	
• 8000～	17(8.76)	
Patient other disease		
• No other disease	59 (30.1)	
• One diseases	59(30.1)	
• Tow diseases	58 (29.59)	
• Three diseases	16 (8.16)	
• Four diseases	4 (2.04)	
Number of Hospitalizations	3.55 (3.7)	
New York Heart Association		
• Class I	19 (10.05)	
• Class II	70 (37.04)	
• Class III	65 (34.39)	
• Class IV	35 (18.52)	
Patient Ejection Fraction	51.37(16.9)	
Course of disease	1610.05 (2407.49)	
Relationship to Patient		
• Spouse		68 (34)
• Mother /father		12 (6)
• Son/daughter		92(46)
• Brother/sister		7 (3.54)
• Son in-law or daughter in-law		11 (5.5)
• Else		10(5)
Other caregivers		1.33 (1.27)
Duration of caregiving		372.85 (1280.7)
Daily time		14.84(8.19)
Caregiver attitude for giving care		
• Very important and I do it from my heart		116 (58.88)
• It's my responsibility and I should do it		74 (37.56)
• I have to do it because I don't have other choice		7(3.5)
Caregiver Health Problems		1.26 (0.53)
Cohabit		
• Yes		120 (60)
• No		80 (40)

Table 2 Quality of life score in the eight dimensions of SF－36 in Patients with heart failure and their family caregivers.

SF-36 domain	Patient Mean ± SD.	Family Caregiver Mean ± SD.	Mean Difference	t	P
Physical Functioning	46.13±27.3	82.93± 9.27	-36.8	-18.05	0.000
Role Physical	24.63± 39.59	53.8± 42.51	-29.17	-7.09	0.000
Bodily pain	48.88±27.54	78.94±19.69	-30.06	-12.56	0.000
General health Perceptions	45.80± 20.79	63.96± 20.92	-18.16	-8.71	0.000
Energy Vitality	42.65±21.78	74.13±16.19	-31.48	-15.77	0.000
Social functioning	59.76±26.52	60.07±21.14	-0.31	-0.13	0.89
Emotional role	49.16±40.61	49.8± 42.7	-0。64	-0.15	0.88
Mental Health	70.33±17.84	70.99±16.34	-0.66	-0.39	0.069
Physical Component Summary	41.62±21.18	70.7 ± 16.4	-29。08	-15.25	0.000
Mental Component Summary	53.54±20.43	64.1± 17.7	-10．56	-5.45	0.000
Total Quality of life score	48.51±21.24	66.8± 16.9	-18。29	-9.64	0.000

Independent T- Test

Table 3 The relation between socio-demographics (gender, education level, marital status, employment status and NYHA)and total quality of life for patient

Patient characteristics	Mean (SD)	T or F stat.	P value
Gender			
• Female	• 44.509 (21.608)	-2.51	0.0128
• Male	• 52.408 (22.33)		
Educational level			
• Illiterate	• 44.033(25.5068)	3.05	0.0116
• Primary school	• 42.604(20.136)		
• Junior middle school	• 49.34(22.02)		
• Senior middle school	• 46.739(19.584)		
• Diploma	• 60.87(21.54)		
• High education	• 40.458 (28.014)		
Marital status			
• Married	• 47.612(22.381)	0.49	0.6257
• Unmarried	• 50.318(22.48)		
Employment status			
• Employed	• 55.006(24.23)	3.73	0.0003
• Unemployed	• 12.038(21.471)		
New York Heart Association			
• Class I	• 48.2467(21.19777)	0.16	0.9245
• Class II	• 48.2479(20.9337)		
• Class III	• 46.0029(24.4221)		
• Class IV	• 48.5589(21.0904)		

ANOVA Test, Independent T- Test

Table 4 the relation between socio-demographics (gender, education level, marital status, employment status and NYHA) and total quality of life for family caregiver.

Family caregivers characteristics	Mean (SD)	T or F stat.	P value
Gender			
• Female	59.476(17.825)	-6.18	0.0001
• Male	-13.79(15.468)		
Educational level			
• Illiterate	60.063(5.745)		
• Primary school	68.016(13.89)		
• Junior middle school	65.339(17.064)		
• Senior middle school	64.617(17.353)	0.93	0.4624
• Diploma	70.982(15.914)		
• High education	68.641(18.636)		
Marital status	2.9467(16.866)		
• Married	69.31(17.368)	0.84	0.3995
• Unmarried			
Employment status			
• Employed	66.647(18.591)	0.17	0.8640
• Unemployed	0.939(18.041)		
New York Heart Association			
• Class I	72.526(14.855)		
• Class II	67.932(17.07)	1.09	0.3530
• Class III	66.069(16.793)		
• Class IV	64.436(17.184)		

ANOVA Test, Independent T- Test

Table 5 the correlation between patients' QOL and caregivers' QOL

Patients and family caregivers QOL	Correlation	P value
Physical Functioning	r = -0.13132	0.0638
Role Physical	r = -0.04581	0.5195
Bodily pain	r = -0.04066	0.5676
General health	r = 0.02155	0.7620
Energy Vitality	r = 0.04002	0.5737
Social functioning	r = 0.00782	0.9125
Emotional role	r = -0.05761	0.4177
Mental Health	r = 0.02194	0.7578
Physical Component Summary	r = -0.09409	0.1851
Mental Component Summary	r = 0.02971	0.6763
Total Quality of life score (sf36)	r = -0.05709	0.4220

r: Pearson Correlation Coefficient